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### Making sense of bodily sensations

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*Published in:*  
Social Science and Medicine

*DOI:*  
[10.1016/j.socscimed.2018.12.034](https://doi.org/10.1016/j.socscimed.2018.12.034)

*Publication date:*  
2019

*Licence:*  
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*Document Version*  
Peer reviewed version

[Link to publication in Discovery Research Portal](#)

*Citation for published version (APA):*  
Macdonald, S., Conway, E., Bikker, A., Browne, S., Robb, K., Campbell, C., Steele, R. J. C., Weller, D., & Macleod, U. (2019). Making sense of bodily sensations: Do shared cancer narratives influence symptom appraisal? *Social Science and Medicine*, 223, 31-39. <https://doi.org/10.1016/j.socscimed.2018.12.034>

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# Accepted Manuscript

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PII: S0277-9536(18)30717-2

DOI: <https://doi.org/10.1016/j.socscimed.2018.12.034>

Reference: SSM 12093

To appear in: *Social Science & Medicine*

Received Date: 16 February 2018

Revised Date: 4 December 2018

Accepted Date: 23 December 2018

Please cite this article as: Macdonald, S., Conway, E., Bikker, A., Browne, S., Robb, K., Campbell, C., Steele, R.J., Weller, D., Macleod, U., Making sense of bodily sensations: Do shared cancer narratives influence symptom appraisal?, *Social Science & Medicine* (2019), doi: <https://doi.org/10.1016/j.socscimed.2018.12.034>.

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**Making sense of bodily sensations: do shared cancer narratives influence symptom appraisal?**

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ACCEPTED MANUSCRIPT

**Making sense of bodily sensations: do shared cancer narratives influence symptom appraisal?****Abstract**

Though new or altered bodily sensations are a common occurrence they rarely transition to biomedically defined symptoms. When they do, sensations are subject to an appraisal process that can culminate in help-seeking. The transition has particular relevance for cancer diagnoses. Studies of 'symptom appraisal' in cancer patients typically conclude that failure to regard sensations as serious or 'symptom misattribution' results in lengthier help-seeking intervals. Though multiple influences on appraisal processes are acknowledged, including the socio-cultural context, detailed description and analyses of how socio-cultural factors shape appraisal is lacking. In this paper we explore one substantial component of the sociocultural context, namely, publicly recognised shared cancer narratives, and their impact on appraisal. We undertook a secondary analysis of 24 interviews with Scottish colorectal cancer patients originally completed in 2006-2007. Our analysis showed that fear, death and severity dominated cancer narratives and were frequently restated throughout interviews. Yet, early bodily changes were often mild and vague, were commonly experienced in the context of 'feeling well' and failed to match preconceived ideas of what cancer 'feels like'. Moreover, few perceived themselves to be 'at risk' of cancer and diagnoses were characterised as 'shocking' events. Participants engaged in self-monitoring strategies and severe or painful changes prompted help-seeking. Far from misattributing symptoms, responses to bodily changes were sensible and measured; responses are particularly apt in relation to current policy rhetoric, which urges measured use of services. Our findings have resonance across healthcare settings as patients are required to negotiate a narrow and challenging space when making decisions to seek help. There is a pressing need for a more realistic approach to symptom appraisal in order to reduce help-seeking intervals. Future awareness campaigns should emphasise the importance of vague/minor bodily changes although this will necessitate discussions with health professionals on referral thresholds to achieve earlier detection.

Keywords

United Kingdom

Bodily sensations

Cancer narratives

Symptom Appraisal

Help-seeking

Colorectal cancer

Introduction

New or unexpected sensations that ‘come with having a body’ (Hallowski 2006) are a regular occurrence, and, for most of us, they trigger a series of internal classificatory questions. Such questions, consciously or unconsciously, focus on severity, persistence and appropriate action. In the vast majority of cases sensations will pass and result in no action. Continued or additional sensations are likely to activate a ‘wait and see’ response, bound by internal limits. If sensations persist and limits passed, the embodied feelings iterate eventually into what biomedicine labels, symptoms.

The transition from sensations to symptoms is unlikely to be linear. Rather, individuals draw on existing knowledge, previous experience and explanatory frameworks when interpreting sensations and revise explanations in light of changes or additional information. An often elaborate interpretive process underpins decisions to seek professional advice and help.

Such decisions, often termed help-seeking or illness behaviour, has been subject to analyses across social science and health related disciplines. Attempts to model, anticipate and explain patterns of help seeking or illness-specific help-seeking dominate the literature. There is, though, a tendency for

focus to remain firmly within disciplinary silos, remaining within psychological or sociological mind-sets, rather than 'cross-referencing' to provide a more rounded explanation of help-seeking (Wyke 2013). Irrespective of discipline, there are areas of broad agreement; first, timely and appropriate help-seeking is associated with better outcomes for patients and second, the influences on the help-seeking transition are many, and include micro, meso and macro level factors (Wyke 2013). Our focus in this paper is on macro level factors; in this context we use 'macro' to denote shared public understandings of cancer, rather than broader structural determinants. Our interest is in how shared understandings direct and shape perceptions of risk and are influence the response to bodily sensations. Ultimately we wish to explore how a deeper understanding of macro-level collective frameworks might, in combination with the micro, assist in further elucidating help-seeking.

For scholars with an interest in cancer diagnoses the help-seeking transition has particular relevance. Relationships between stage of disease at diagnosis, outcomes and survival are well-established (Richards 2009; Tørring et al 2013). That we can diagnose cancer ever earlier dominates policy rhetoric and implicit in this rhetoric is that the public should be equally immersed and keep pace. It is important to recognise though that most cancer is diagnosed following the presentation of specific symptoms (Hamilton 2009). As a result, attempts to encourage early detection and diagnosis foreground individual response to sensations or symptoms and considerable effort is expended raising awareness of 'alarm symptoms' albeit with limited effectiveness (Austoker et al 2009). Despite such efforts new or unusual sensations do not always illicit a timely response. Explanations of 'delays' typically emphasise patient level factors and often conclude that 'symptoms' are not regarded as serious or are attributed to other things. Such findings are consistent across cancer sites and have been repeatedly reported over time (Macleod 2009; Smith 2005), suggesting an impasse around symptom appraisal. Although there is widespread recognition that bodily sensations are appraised and interpreted in a socio-cultural context, how contextual factors are operationalised in the appraisal process remains under-described and poorly defined. Our aim in this paper is to shift attention away from the individual and consider how cultural influences shape the interpretation of

sensations. Principally our interest is in how common public understanding and narratives of cancer, an illness characterised as severe, uncertain, unpredictable and fatal, shape and influence the response to bodily sensations. We draw on retrospective accounts of colorectal cancer patients to explore the ways in which shared understandings of cancer and cancer risk feature in the transition to help-seeking.

### **Sensations, symptoms and help-seeking in cancer**

Studies of symptom appraisal, help-seeking and subsequent diagnosis of cancer are by no means new. As far back as 1938, Pack and Gallo indicated that ‘delays’ occur in the detection and diagnosis of cancer. And while they acknowledged that patient, practitioner, and hospital system factors all impede detection, patient factors were most significant (Pack and Gallo 1938). ‘Delays’ were associated with patients’ failure to appreciate the seriousness of bodily changes.

Much of the language of, and thinking around, delay has progressed since the 1930s (Weller 2012), yet Pack and Gallo’s findings have enduring resonance. Prolonged time to presentation remains common and varies by cancer site (Lyrtatzopoulos 2015). Studies that describe and interpret ‘delay’ highlight the significance of socio-demographic factors including age, sex, education level and marital status, though their relative importance differs across cancer sites is inconclusive (Smith 2005; Mitchell 2008, Macleod 2009). More conclusive are awareness-related and psychosocial factors which indicate consistently, just as Pack and Gallo did, that failure to appreciate the seriousness, or misattribution of symptoms, results in lengthier intervals between recognition and presentation (Forbes et al 2014, Smith 2005, Chapple et al 2004, Corner et al 2006). Optimistic bias, coping, fear, misattributing or normalising symptoms and failing to appreciate seriousness are all apparent during appraisal (Chapple et al 2004; Corner et al 2006; Smith et al 2005; Gascoigne et al 1999; de Nooijer et al 2001a; de Nooijer et al 2001b; Ristvedt and Trinkaus 2005; Evans et al 2014). Patients, drawing on past experience, employ self-monitoring and invariably report prompt presentation in response to ‘severe’ changes (Corner et al 2006; Evans et al 2014). The common



features of appraisal can be distilled to knowledge, attention, expectation and identity (Whittaker et al 2015b) and all are brought to bear in the appraisal process. Such a breadth confirms the complex nature of appraisal but concentration remains located at the micro-level and simply characterising this as 'delay' is problematic and fails to capture the often convoluted help-seeking process (Dobson et al 2014).

The enduring focus on symptoms in studies of presentation and detection, as well as dominance of misattribution or misinterpretation as explanation, confirms the impasse. Models of 'delay' have categorised the early part of the cancer journey (Safer et al 1979, Andersen et al 1995; Walter et al 2012), and attempt to better capture the myriad possible influences on the time to diagnosis but the models remain largely classificatory. Moreover, the modelled approach is predicated on two assumptions: a) there is deliberate or conscious action on the part of the patient, and b) the pre-diagnostic process is largely linear and assumes an optimal pre-diagnostic pathway (Granek and Fergus 2012).

Critiques of appraisal studies (Andersen 2009; Andersen et al 2010; Corner and Brindle 2011) have highlighted that, despite recognition that the socio-cultural context is significant, there is a relative dearth of discussion specifically characterising the context necessary to provide social depth to analyses. Within anthropology there is a long tradition of locating the appraisal of bodily sensations within the socio-cultural realm. Discussing the appraisal of sensations, Hay concludes: 'The interpretation is not equivalent to the raw sensation; it is a culturally informed interpretation of its relevance.' (Hay 2008). Others, notably Kleinman (1981), demonstrate that sense-making is facilitated by consulting a personal portfolio of experience that utilises examples from micro, meso and macro levels. Symptom interpretation is therefore influenced by prior knowledge, which is socially and culturally contingent.

#### **Everyday understanding of illness, public narratives and candidacy**

The emphasis is firmly on the socio-cultural in Davison and colleagues' discussion of lay epidemiology (Davison et al 1991). Lay epidemiology, like its mainstream counterpart, draws on observations within wider communities and societies to estimate individual risk. Importantly, Davison shows that observations at micro, meso and macro levels, that is individual; community and culture amalgamate to provide a collectively recognised risk profile or candidate. In reapplying Davison's concept to explore the utility of lay epidemiology in the context of cancer, Macdonald, Watt and Macleod (2013) conclude that while the information gathering process mirrors that described by Davison, cancer candidacy inhabits a different space. Rather than a clearly fixed risk profile, strongly aligned with mainstream risk, cancer discourses are dominated by a series of common narratives: randomness, unpredictability, fear, severity and tragedy. Unlike coronary candidates cancer candidates are ambiguous (with the exception of smokers) with no clear pathways to individual risk factors which are often discounted in favour of luck as a plausible aetiological explanation. 'Unwarranted survivors' (i.e. those who 'do all the wrong things') and 'anomalous deaths' (i.e. those who are healthy and not at risk) are therefore writ large in public narratives and collective understandings of cancer candidacy.

That cancer events are discussed in this context is important. The emphasis on early detection via timely presentation requires a keener understanding of the wider context in which bodily changes are appraised. Public narratives that underline severity, tragedy and luck in relation to cancer inform collective notions of cancer candidacy that are culturally produced and reproduced and influence personal risk estimation. Such narratives, we propose, feature in responses to bodily changes. Risk appraisal and appraisal of bodily changes are intertwined. With the exception of 'obvious' changes, such as breast lumps (widely recognised as an alarm symptom and trigger prompt help-seeking (Quaife et al 2014), we suggest that if risk of cancer had not been considered previously that cancer may not be considered when evaluating new bodily sensations.

## Methods

*Analytic approach: secondary Analysis*

Although secondary analysis has well-documented limitations (Heaton 2004; Mauthner et al 1998), it is increasingly recognised as an efficient and effective research approach. Using already available data minimises burden for research participants and reduces research time; all of which are particularly relevant when examining longitudinal life experiences, such as diagnosis and treatment of chronic and acute conditions (Ziebland and Hunt 2014). We conducted what Heaton (2004) refers to as a supra-analysis, which re-analyses data, gathered for a different purpose to establish new concepts or theories (Heaton 2004). Secondary analyses are strengthened by drawing on theory to provide a new analytic lens from the outset to maximise the validity and applicability of the analysis as it addressed the issue of context, often thought to be a limitation of secondary analysis (Moore 2007). We undertook a secondary analysis of longitudinal interviews with colorectal cancer patients, which originally sought to explore patients' experiences of the primary and secondary care interface (Browne et al). Two of the authors (SB,UM) were involved in the original study and familiar with the data, which contained rich accounts of help-seeking, the time around diagnosis and individual patient pathways. Cancer was presented as a story, encompassing the period from pre-diagnosis until the completion of treatment (Salander 2002). Data were initially scoped by SM and SB to establish whether the data were detailed enough to warrant re-analysis. As our previous work on candidacy had focused on lay rather than patient perspectives, we sought from the outset to apply the concepts of cancer candidacy to patients' retrospective accounts of help-seeking. We therefore initiated analysis by thematically coding the data to three broad a priori themes: risk and candidacy, sensations and symptoms and meaning of cancer, which referred to discussions of shared cancer narratives, which together formed the basis of our analytic lens. The analysis was iterative, with the relative importance of themes and sub-themes shifting as analysis progressed. We were mindful when revisiting the data that studies of symptom appraisal frequently rely on retrospective explorations of patient experiences that seek to illuminate delays. Such experiences are likely to be obscured, or at least re-evaluated, in the context of a cancer diagnosis. Although we were also

evaluating retrospective reflections we believe that that the original focus on the experience of health services, rather than help-seeking, removed the pejorative focus on delay. Accounts of symptom appraisal and help-seeking emerged naturally. As with other studies that explore retrospective accounts there is the potential for recall bias as well as moderator bias (Althubaiti 2016). We were mindful that participants' were typically positive about their experiences and most were recovering well post-treatment. Cancer is as we have outlined, associated with fear or dread and we considered the impact of participants' emotions on the generation of data. We were aware that accounts offered might have been different if prognoses outcomes had been more negative. Moreover, we should stress that in re-analysing data collected for a different purpose, some of the detail around help-seeking and timing is lacking.

#### Interviews

Twenty-four participants were recruited for the original study, all of whom had been diagnosed with and received treatment for colorectal cancer. All were symptomatic and none of the participants' cancers detected via screening. Participants were recruited from hospitals across Glasgow, and were purposively sampled to represent a varied range of characteristics such as age and sex, socioeconomic status and co-morbidity. Those who took part were aged between 34 and 84 years (though only three participants were under 50), comprised 16 women and eight men, and represented the full range of clinical stages. The first wave of data were gathered between 2006 and 2007. Interviews began with a general question around the participants' trajectory, for example 'Can you tell me about your cancer experience so far?', and in response, participants typically presented a narrative that began with early sensations and the recognition that something was 'wrong'. Second interviews with nineteen of the original participants were carried out twelve months later.

Although data from the second interview was not excluded from our analyses, much of the discussion of the time before diagnosis took place in the first interview. In six of the interviews spousal pairs i.e. husband and wife, were present at the interview, as is evident in data extracts. However, in three of those interviews the spouses did not contribute formally to the interview

process. Two participants died before the second interview, one was unwell at the time of the data collection, and two had moved out of contact. Ethical approval to use the data was sought from the original NHS Ethics committee Scottish MREC A.

### *Analytic process*

The primary researchers (EC, SM) read and re-read all the original data transcripts. As outlined above we built upon a previously developed analytical frame (Macdonald 2013 et al). Yet, the analysis remained flexible enough to allow the inclusion of additional themes. The finalised framework was collaboratively produced and refined by EC and SM and comprised three broad themes: a) perception of *risk*, described through retrospective evaluation of their cancer diagnosis; b) *bodily sensations*, and how both individuals and medical practitioners appraised them, although in addition we sought to discover clues as to c) the broader *meaning of cancer* characterised in accounts. The broad thematic approach allowed us to identify complementary and contradictory narratives and to draw inferences from individual experiences of diagnosis and help-seeking for colorectal cancer. The original study sought to uncover potential differences in perspectives or accounts associated with socio-demographic factors, and because few differences emerged we opted not to interrogate the data for such differences and patterns in this analysis. We used NVivo 10 to organise, code and catalogue the data.

### **Findings**

We present our findings in three overarching categories: meaning of cancer, which captures the broader descriptions of cancer, including publicly shared narratives; perceptions of risk which includes participants' understanding of risk factors associated with colorectal cancer as well as estimations of personal risk; finally bodily sensations, appraisal and symptoms, where detail of

bodily changes and response to those changes, including help-seeking, are outlined. While this linear structure seems not to take account of the complexity of appraisal processes, our aim was to illustrate the significance and pervasiveness of the meaning of cancer contained within explanatory frameworks, which we contest were apparent pre-diagnosis and before the presence of new bodily sensations. As outlined above, our previous work in the area of cancer candidacy established that shared and public narratives of cancer obscured more detailed categorisations of individual cancer candidacy (Macdonald, Watt and Macleod 2013). Public narratives are central to explanatory frameworks, which in turn shape meaning, and, we suggest guide risk estimation and symptom appraisal. Rather than adopting entirely new explanatory frameworks participants' reflections reveal their application of pre-diagnostic explanatory frameworks in making sense of both bodily sensations and subsequent diagnosis.

### ***Meaning of cancer***

In her recent auto-ethnography Grenhalgh (2017) asserts her wish, on receiving a diagnosis of breast cancer, to move away from the tragedy genre to locate her own narrative (Greenhalgh 2017). A considerable proportion of our shared understanding of cancer centres on this tragedy genre – characterising cancer as a severe, painful, fearful, and ultimately fatal illness. Cancer invades the physical, emotional, social and existential life-worlds of cancer patients; a process described by Mukherjee (2010) in the *Emperor of all Maladies* as 'the gravitational tug that pulls everything and everyone into the orbit of cancer' (Mukherjee 2010). Such scale distinguishes the enormity of cancer - a disease that inhabits a particular space in the public psyche. Sontag (1978) traced the culturally embedded symbolism attached to cancer and argued that the metaphors surrounding the illness and their impact on the patient experience were at least as damaging as the illness itself. The dominance of war and battle metaphors reinforces cancer as the enemy (Vrinten et al 2016) and induces fear (Clarke & Everett 2006). The inability to control and therefore fully explain individual cancer cases establishes cancer as a distinctly moral illness (Lupton 1994), and while in some

contexts the presence of cancer has been reduced to good vs. evil (Hunt 1998) it is more usually associated with personal failure (Balmer, Griffiths & Dunn 2014). Attempts to quash such morally loaded attitudes has seen the proliferation of counter narratives, such as the 'hope' narrative, transformative narratives or sporting metaphors (Seale 2001a, 2001b, 2002) but these counter narratives are not without critics (Ehrenreich 2009). Such counter narratives reflect positive advances in cancer treatment and survival in many cancer sites since the 1970s, yet cancer maintains its status as the most dreaded disease (Vrinten et al 2016).

Such narratives and meanings featured in participants' re-analysed accounts. Uniformly diagnoses were met with shock and fear and the implications of diagnoses were collectively understood and explicit. Participants highlighted the symbolism attached to the word cancer: *"it's the word cancer...that's the killer...everybody's like that, the whole family, cancer 'death'...that's what people think"* (pt12 M 48 Dep 5). Thoughts immediately turned to the ungovernable and aggressive illness that quickly spreads (Robb 2014) and participants articulated concerns that the disease had spread and *how quickly it can move...* (pt10 F 69 Dep 5). Participants noted that expressions of fear and dread extended to family members and wider social networks. One participant described her discomfort when colleagues looked at her as though she was 'going to die' ((pt2 F 50 Dep 1.) while another emphasised the taboo attached to cancer, with those around concerned that they 'might catch it'.

Alongside wider shared narratives, participants discussed the impact of cancer on self-identity. With one or two notable exceptions participants talked of the lasting impact of a cancer diagnosis, of being 'defined' by cancer and its permanence; as one suggested she would now always *"have something that says...I am a cancer woman"* (pt2 F 50 Dep 1). Such reflections are weaved throughout sociological studies that seek to uncover the lived experience of cancer (Kerr et al 2018) and originate not only from the biological or physiological impact of cancer but, we propose, the socio-cultural significance of cancer itself.

While we do not claim that these descriptions are new, they do contribute to explanatory frameworks, which are trawled to make sense of altered or new bodily sensations (Dingwall (2001); Kleinman (1981), and Young (1980)). Explanatory frameworks contain an amalgam of information and are not confined to these narratives and metaphors but we propose that perceptions of cancer risk and new bodily sensations are evaluated in relation to, and contingent on, this cultural backdrop.

### Perceptions of Risk

As interviews were conducted post-diagnosis, many participants had had the opportunity to pause and reflect on factors that they felt had caused, or contributed to, their cancer. It was evident that some had appraised factors that may have helped explain their cancer. Participants discussed their diagnosis in a background of what they regarded as protective lifestyle choices and behaviours and were hesitant to see themselves at risk, even after diagnosis. One participant described his lifestyle as 'exemplary' (pt17 M 51 Dep 1), while others emphasised the 'moderate' nature of lifestyle choices and stressed their non-smoking status. The following extract illustrates one participant's estimation of their own cancer candidacy:

*He went "no, no, no (Bangs on table) she eats very healthy, no it can't be she eats very healthy, it just can't be her, she eats salads and rabbit food" it was just like, no he wasn't having that (laughs). It can happen to anybody, you know (pt19 F 53 Dep 1) [participant describes husband's reaction to diagnosis]*

Here, the participant asserts that she was not at risk but she adds 'it can happen to anyone', therefore emphasising the unpredictable nature of an illness replete with anomalies but also allowing her to push against the stigma and taboo associated with cancer; the moral nature of cancer is underlined (Lupton 1994). Even after diagnosis participants distance themselves from cancer risk; while maintaining moral responsibility. Cancer has been associated with personal



weakness (Balmer, Griffiths & Dunn 2014) but the need to demonstrate a morally responsible position also flows from macro-level policies that emphasise individual responsibility in the consumption of health and health care. Individuals are obliged to maximise their ability to maintain good health by being health 'literate', minimising risks to health and engaging and enacting self-monitoring in the face of ill-health (Gray 2009, Schmidt 2007). Those engaging in 'risky' behaviours are aware of the implications, as one participant stated *well, you know, especially I'm a smoker, I'm overweight I know the set-up em and of course it's always, it's never going to be me. (pt21 M 59 Dep 4)*. In suggesting that he knows 'the set-up' but at the same time 'it's never going to be me' highlights the dominance of anomalies in the experience of cancer. Many 'unwarranted survivors' flout behavioural rules and 'get away with it' which reinforces the unpredictability of cancer.

Unpredictability also underpinned discussions of recurrence. Far from heightening their feeling of risk most were sanguine about the possibility of cancer returning. In the aftermath of treatment, many expressed similar attitudes towards the disease as those described on diagnosis: factors out with their control dictated the likelihood of recurrence. Reliance on 'fate' as an explanation for both the original diagnosis and recurrence was common; cancer just 'happens'.

Luck more than risk dominated aetiological conversations; developing the disease has been a result of misfortune, and survival due to serendipity. The prominence of luck in discussions of cancer candidacy serves a useful function for those diagnosed as it distinguishes cancer events as above all, unlucky. Davison and colleagues concluded that coronary candidacy allowed an easy explanation of distressing events (Davison et al 1991). A cancer diagnosis is certainly distressing and the physiological distress coupled with its morally charged nature requires explanation; luck provides a safe space for participants to cope with and come to terms with their illness.

Other risks, particularly that participants had little control over, notably, a family predisposition to cancer did not appear to raise expectations or heighten estimation of risk prior to diagnosis, though some re-evaluated their status post-diagnosis. For example one participant commented on her

'shock' on receiving diagnosis but *I don't know why because...my mother and my brother had it...*" (pt4 F 65 Dep 3), while another suggested that she assumed that her family history heightened her risk of heart disease because of her father's illness despite her grandmother's diagnosis of colorectal cancer, which was *'something I just didn't think was in the family'*" (pt9 F 55 Dep 2).

Family history or hereditary are commonly reported lay aetiological explanations for cancer though often without clear causal pathways (Kenen et al 2003). Those with a positive family history often distance themselves from the risk by emphasising protective behaviours to off-set risk or assigning additional weight to other illnesses that run in the 'other side' of the family (Robb et al 2007).

### **Bodily changes, appraisal and symptoms**

#### *Early sensations and changes*

Common symptoms including changes in bowel habit, rectal bleeding and mild pain were usual. Some reported less obvious symptoms, which were not immediately associated with colorectal cancer, by either themselves or their general practitioner. Very few described the bodily changes as sudden, severe or serious. Instead, accounts indicate that for most, initial changes were mild and vague, unobtrusive and insubstantial. For example, one participant described *"slight bleeding on going to the toilet (pt1 M 75 Dep 5)"* but attributed this to a recent prescription of soluble aspirin. Many others initially attributed altered bowel habits to 'a bug', with one participant describing the change as *"... just like a wee nuisance thing here in my side (pt23 M 76 Dep 4)"*. What these short extracts illustrate is the participants' use of existing explanatory frameworks to explain the sensations they experienced. Attributing changes to 'a bug' or changes in medication are common and usual explanations for what they perceived to be mild changes.

Concerns were often governed by hierarchical notions of severity, with pain and especially significant bleeding at its apex, and in the absence of 'severe' sensations and pain participants *'thought, well it's not anything serious'*" (spouse pt13 M 72 Dep 5). Distinguishing sensations as

'nothing' and comparing these with well-publicised cancer symptoms, for example unusual bleeding indicates that bio-medicine is referenced and interweaved throughout appraisal (Armstrong & Murphy 2008). Participants often arrived at what they regarded as reasonable explanations that were located in the bio-medical sphere. Importantly, far from ignoring sensations they were attuned to them, maintaining their status as responsible patients who did not shrug off cancer symptoms.

For most early changes did not warrant immediate help-seeking. As the extracts below show, there was no immediate need to **'bother'** the doctor or it **'wasn't worth'** going to the doctor but as additional, more distressing changes occurred active help-seeking was triggered:

*Well, obviously I had a change of bowel symptoms to begin with and it was like kind of flatulence and it kind of bothered me for a couple of years that but they just kind of kept saying it was irritable bowel or it was this or it was that but I never put it down to ever anything like that [cancer] because I had no other symptoms, I wasn't in pain or anything like that at all. Then ... I passed blood from my back passage and it was just horrendous so I went down to the Doctors and he whipped me into the hospital (pt16 F 37 Dep 4).*

Reluctance to bother the doctor or experiencing changes not worth seeking help for reflects the desire for measured use of healthcare (Brandner et al 2017). Beyond negotiating help-seeking decisions, these often mild, vague and unobtrusive symptoms were not commensurate with the wider perceptions of cancer as a severe and fatal illness (Balmer, Griffiths and Dunn 2014, Lewis et al 2017). Severity and irregularity are important. Salander's study of symptom appraisal in brain cancer found that every day symptoms such as headaches were frequently attributed to minor changes or social reasons, such as stress, but less usual symptoms, notably seizures, prompted help-seeking as they were difficult to easily explain (Salander et al 1999).

*Interpreting changes and bodily sensations*

Early sensations were contextualised within existing frames of previous health experiences. Several, for example, had a history of minor, benign bowel complaints – most commonly haemorrhoids – and assumed that similar sensations had similar origins. Some were in receipt of treatment for pre-existing illnesses, which proved a complicating factor in isolating issues that might indicate additional disease. One participant already diagnosed with cancer, in a proximate site, found that the origins of new sensations were blurred:

*“I have had some bleeding but I didn’t know it was that I thought it was just connected to maybe haemorrhoids or something I knew I had more back pain and I didn’t know if it was coming from the womb...I still don’t know if that was coming from the bowel or the womb cancer” (pt9 F 55 Dep 2).*

More commonly, others initially assumed that changes, albeit dramatic, were consistent with their age or stage of life. Being generally run down, ageing or changes in dietary habits were all cited as reasonable initial explanations for encountering what were, mostly, mild and untroublesome changes. Fatigue was most commonly associated with ageing, which has been reported elsewhere: *I really started to feel done in, absolutely no energy at all, you put a lot of that down to your age, you know, and how busy you’ve been at work and things like that but there was an underlying cause to it which I just didn’t recognise at the time although hindsight’s always twenty-twenty vision isn’t it? (pt22 M 55 Dep).*

What emerges from interpretation is that catalogue of changes and sensations occur simultaneously and are layered to retrospectively make sense of the cancer diagnosis. One participant experienced ‘sweats’ that she initially attributed to ageing but post-diagnosis recalled by her brother-in-law, who was also diagnosed with colorectal cancer had similar sensations; the change only assumes importance in the light of diagnosis.

*Feeling well*

At least equally significant was participants' assessment of their overall wellness in the time before diagnosis. While all reported experiencing physical symptoms, many described their overall state of health at that time, and did so in terms of embodied *feelings*. Feeling '*pretty good*' and being able to continue with daily activities signified wellness and was at odds with what was happening within their body:

*I knew there was something no right with my bowels but I didn't feel ill. In fact I would have said weeks before I mean I was here, there and everywhere, you know, I didn't feel as if there was anything wrong with me. (Pt4 F 65 Dep 3)*

Feeling well extends beyond physical feelings and there was no sense that participants were 'containing' symptoms (Andersen et al 2010). There is a tacit assumption in participants' accounts that a uniformly recognised serious, life-threatening illness as cancer would present with explicit and severe symptoms, rather than the mild, 'niggling' most encountered.

#### *Unwellness*

Just as some participants reported feeling well, which influenced their attribution of bodily changes, others reported feeling 'unwell', which had an equally important impact on interpreting their experience. Many were engaged in persistent help-seeking and irrespective of the vagueness of symptoms participants were aware of an underlying sense of *unwellness* or a feeling that something just '*wasn't very right*' (pt13 M 72 Dep 5). Moreover, this feeling often contradicted professional assessments. For a few participants, who reported a long, protracted help-seeking process pre-diagnosis it was often this sense that something wasn't right that allowed them to tenaciously and repeatedly seek professional advice.

#### *Help-seeking*

During first consultations with general practitioners (GPs) an array of benign explanations were offered and for most referral to specialist services did not occur following the first consultation, but

following a short period of watchful waiting. Nevertheless most received what they regarded as timely referral for further investigations. In a small number of cases, there were significant lags between primary consultation and secondary referral, and a general reticence to investigate further:

*Oh irritable bowel syndrome that was what it was. And I looked up irritable bowel syndrome and it wasn't because you have pain with that, and I had no pain well so it said in a woman's magazine or whatever I read. So I think GP's need a kick up the backside, some of them ... (pt8 F 67 Dep 2).*

While the majority of GP backed up their initial assessment with onward referrals, in two cases misdiagnosis continued over a prolonged period of time, despite repeated presentations with increasingly problematic symptoms.

#### *Timeliness of help-seeking*

As the original study did not seek to assess help-seeking or timescales it was not possible to, and nor did we seek to, explore potential 'delays' in the process of appraisal. Participants typically used timeframes to contextualise help-seeking and the majority described little or no delay in seeking medical advice and presented accounts of prompt presentation. Implicit in some accounts was the questioning whether they may have known earlier, whether they had missed vital clues, and with one exception, it appears that nothing was missed. There were exceptions. One participant expressed regret that he had not visited his doctor earlier, but even when re-evaluating his disease trajectory, insisted that, given the nature of his single symptom he "*just wouldn't have gone with [that symptom]*" (pt18 M 81 Dep 1). Prolonging help-seeking was described with regret:

*But I kind of blame myself ... I should have went to the Doctor earlier and I'm telling anybody that's listening "Don't wait if you don't feel right if you go to the toilet and you know it's not right and you don't do anything about it you're stupid" when you think about it (pt1 M 75 dep 5).*

The extract captures the participant's feelings of responsibility at not seeking help earlier even in the absence of what might be regarded as obvious symptoms. Instead he simply did not 'feel right', and

this he retrospectively suggests should trigger help-seeking. Yet as we have seen participants in this and other studies sought more concrete and incontestable symptoms in the process of appraisal. The feeling of personal responsibility is pervasive. Even when professionals were held responsible for delays this was often paralleled with regret that, they had not been more emphatic in directing the GP to request investigation more quickly.

## Discussion

Cancer inhabits a unique space in the public psyche (Sontag 1978) and although public narratives have altered and shifted more recently there is no doubt that cancer holds a shared meaning (Greenhalgh 2017). Against a backdrop of well-rehearsed public or shared cancer narratives which emphasise the random and unpredictable nature of cancer our analyses of colorectal cancer patients' retrospective accounts of help-seeking and experience of cancer diagnoses suggest that until confronted with illness, few saw themselves as being at risk of colorectal cancer. Although some were cognisant of behavioural risk factors such as diet or alcohol consumption, only a handful of participants identified themselves as being at risk in this regard. More usually, accounts illustrate that diagnoses were unexplainable and attributed to luck, thus emphasising the unpredictable and random nature of cancer dominant in popular and shared cancer narratives. Explaining illness events satisfactorily requires more than an awareness of risk factors. If we are to make sense of why particular individuals succumb to particular illnesses at a particular time we need more detailed but nuanced explanatory frameworks (Davison 1991; Hunt 1998). For Davison, candidacy provides explanation, while for Hunt, moral causality is enacted; both are thought to distil the idea that illness is simply arbitrary. Yet, in our data, we see that luck, a wholly arbitrary concept, dominates explanations. Luck we propose allows participants to distance themselves from moral causality and cancer candidacy.

Reluctance to appreciate personal risk is not surprising, not only because the general awareness of colorectal cancer risk factors is low (Anderson 2015) but also because recognising personal risk is more challenging than identifying risk in others (Davison 1991). Assigning personal candidacy confronts wider perceptions of self, and this is writ large in such a morally loaded illness as cancer (Lupton 1995). Given the recent well-publicised campaigns seeking to raise awareness of associations between cancer and obesity – equally morally charged (Bissell et al 2016), it is interesting to consider how this might impact future narratives around candidacy and risk.

How risk or threat is perceived is interwoven with the interpretation of new or unusual bodily changes and together influence help-seeking behaviour. Our findings concur with and contribute to others' that demonstrate that early bodily sensations and changes are rarely regarded as serious (Whitaker 2015). Implicit in accounts is the belief that sensations or changes did not match participants' understanding of how cancer would manifest. Few participants considered the changes to be anything serious and it is possible that the prevalence of the symptoms, such as abdominal pain or 'slight' rectal bleeding, in the wider community may discourage immediate help-seeking. Many engaged in self-monitoring and watchful waiting and sensations were appraised in the context of feeling well, though when changes 'didn't feel right, help-seeking was progressed in spite of only vague or minor changes. A process of layering where sensations persist, become more troubling and/or are joined by additional changes characterise accounts and illustrate the transition from bodily sensations to symptoms (Seibaek 2011). Locock describe an assemblage of clues and cues pre-date but allow patients to anticipate diagnosis where no single clue or cue is predictive. Though participants rarely anticipated diagnosis a similar assemblage of sensations and feelings, gathered retrospectively occurs to underline the processual nature of help-seeking. Additionally, sensations or changes assume more prominence post-diagnosis and retrospective clues to subsequent diagnoses are later re-evaluated (Alonzo 1979). Other sensations, later acknowledged as symptoms, were subject to the age-illness rule (Scott et al 2012) and were normalised (Hall et al 2015; Brindle et al 2012 MacLachlan et al 2015). Time and persistence are significant and there are many examples of



watchful waiting as a management strategy (Birt et al 2014). Fear or perceived risk is thought to both motivate and discourage help-seeking (Dubayova et al 2010; Mitchell et al 2008; Macleod et al 2009) but did not appear to have a role for our participants. Many participants described feeling well (Brindle et al 2012; Hall et al 2015; MacArtney et al 2017) experiencing only mild or 'niggling' changes, which were appraised in the wider context of how they 'felt'. Alarming sensations legitimise help-seeking and the participants' accounts hint at the reluctance to seek help for minor problems (Whittaker et al 2015; Cromme et al 2016; Llarnwarne et al 2017; MacArtney et al 2017). International comparative studies show variations in respondents' willingness to 'bother' their doctor (Forbes et al 2013; MacArtney et al 2017) and in emphasising the 'mild' rather than troubling nature of bodily sensations, participants attempt to adhere to the responsible and moral patient typology demanded within the UK health care system. Recent analyses have focused on 'the good patient' or 'good citizens', which characterises those, especially in societies built around social welfare, that both appreciate and value access to services but are cognisant that such services should be used responsibly (Llarnwarne et al 2017; Offersen et al 2017; Maclean et al 2017; Cromme et al 2016). In the UK, current rhetoric represents the National Health Service as a scarce resource that requires protection by all those that have an interest (Kings Fund 2017). Guidance emphasises appropriate service use (NHS Choices 2015) and self-management of minor illness (Choose well this winter 2016)), yet simultaneously urges appropriate and timely help-seeking for other bodily changes (Be Clear on Cancer 2010; Detect Cancer Early). Failing to seek help has moral implications, both personally and in policy terms. At a micro level seeking help too late can impact greatly on patient outcomes; at a macro level later diagnoses contribute to poorer national survival rates and outcomes. Patients are therefore expected to negotiate a fairly narrow and challenging space if they are to maintain responsibility. This negotiation is contingent on how they *feel* and in reality many feel *well* and do not regard the sensations they are experiencing as severe (Brindle et al 2012; MacArtney et al 2017). Matching symptom severity with severity of disease is complex: patients are encouraged to self-manage and implicit in patient accounts is the incongruity between

the sensations they experienced and what they anticipated cancer would feel like (Scott et al 2005, Levin et al 1985). Indeed these data show that personal explanations were typically reinforced – and therefore validated - by general practitioners at the first consultation; professionals too are engaged in the pre-diagnostic ‘dance’ (Locock et al 2016). What emerges are pictures of progressive build ups towards a suspicion of cancer that is multi-layered rather than linear.

Our approach is not without limitations. One clear challenge, which is common across studies of symptom appraisal, is the use of patients’ retrospective accounts, which are given post-diagnosis. Patients cannot, when reflecting on the time pre-diagnosis un-know their subsequent diagnosis. However, our use of data gathered for a separate and distinct purpose, thereby removing the focus on delayed help-seeking, mitigates the challenge. Moreover, we suggest that just as they cannot un-know their diagnosis, neither can they un-know their existing views and shared understandings of cancer, which are important influences on the perceptions of risk and the appraisal process. Additionally, in our reanalysis, we did not seek to tease out differences according to socio-economic status, gender or ethnicity but it is worth noting these factors may contribute additional layers to perceptions of risk, the appraisal of sensations and help-seeking. Multimorbidity, which increases the likelihood of competing sensations and consequently symptom misattribution, is more common in less affluent communities (Barnett 2012). Health care use is socially patterned and ease of access through health systems is not socially neutral (Dixon-Woods et al 2006). Gender influences consultation patterns (Wang 2013) and the experience of coping with cancer (Emslie et al) and it has traditionally been assumed that men are more likely to prolong help-seeking (Smith, Pope and Botha 2005). More recent consideration of symptom appraisal has suggested that the importance of gender has been over-stated (Maclean et al 2017). Moreover, given the composition of the original sample, perspectives of non-white communities are missing and is an important limitation. Perceptions of risk and interpretation of bodily changes are heterogeneous and nuanced to reflect beliefs across communities and cultures (Pfeffer 2004, King-Okoye, Arber & Faithful 2017)

Though our findings echo those of many appraisal studies they also represent an important departure. Existing appraisal models emphasise immediate personal environments and although they acknowledge the importance of the cultural factors rarely are broader influences afforded deeper reflection. Shared understandings of cancer, as demonstrated in our findings, in particular the collective and implicit recognition of what cancer means beyond the biological sphere represent social information (Leventhal 2003). Common cancer narratives and metaphors shape not only the experience of the illness, as Sontag suggested, but also influence, we propose, the appraisal period. Participant accounts contain descriptions of bodily sensations which they believed to be 'nothing', 'mild', 'not drastic' which match the well-rehearsed conclusions that symptoms were not regarded as serious or were misattributed. Yet such conclusions fail to ask substantive question: why are sensations not thought to be serious? We contest that sensations do not align with accepted and collectively understood ideas of what cancer - a severe illness - should 'feel' like and therefore, participants did not recognise themselves as cancer candidates, either in relation to their perceived risk of colorectal cancer or the embodied sensations they describe.

## Conclusions

Appraisal studies typically conclude that individuals misattribute or misinterpret bodily sensations. Implicit in conclusions that underline misattribution or misinterpretation is that people, by failing to recognise something obvious, are getting something wrong or denying the existence of bio-medically focused symptoms. Our data contest this assumption. We show that participants' responses to new bodily sensations are reasonable and are informed by an evidence base that pools past experience and wider socio-cultural explanations. Others have demonstrated similar processes in the experiences of those living with long-term conditions (May et al 2016). The divide between the popular and professional sectors where sense-making occurs is clear (Kleinman et al 1978).

Our findings have implications for researchers and health care systems. Just as the Aarhus statement (Weller 2012) encouraged a departure from the term 'delay' which was thought unhelpful in the context of help-seeking, there is room to move away from 'misinterpretation' as the default conclusion in studies of appraisal. Misinterpretation infers culpability on the part of the patient; in reality most early sensations *are* mild or vague. Such a move however poses a challenge for those seeking to raise awareness of 'symptoms' in the community. Acknowledging that early bodily changes may feel like *nothing*, particularly given that symptoms associated with colorectal cancer are common, risks raising fear within the community. Nevertheless, there is a need to be more convincing about *vague* bodily changes and to be clear that changes, which may indicate cancer may not, at first, *feel* serious. Such a move requires a considerable shift for patients for whom feeling well is at odds with our shared understanding of cancer as a most grave disease. International variations in cancer outcomes and survival, notably within the International Cancer Benchmarking Partnership (ICBP) have triggered a raft of ameliorative measures, aimed at reducing time to diagnosis. In those countries where overall survival is poorest (UK and Denmark) aims to lower the threshold for referral by general practitioners and therefore extend access to specialist investigation should produce benefits (NICE 2015; Brown et al 2014). While the need to improve time to diagnosis is most pressing in those countries where survival is poorest, our findings have implications across healthcare systems, regardless of outcomes. If time to diagnosis is to be reduced we need to focus attention not just on system change but also on patient experience. As such careful thought needs to be given to patient thresholds for help-seeking as well as thresholds for safety netting, referral and subsequent investigations. A more realistic approach that is cognisant of the often opaque nature of altered or new bodily sensations is necessary if awareness raising measures are to produce tangible outcomes.

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### Highlights

Patients have been shown to misinterpret symptom seriousness and delay help-seeking.

Symptom appraisal is socially contingent but the social context is under-described.

Shared cancer narratives, reproduced in social contexts, shape appraisal processes.

Mild, vague sensations were at odds with ideas about cancer – a most severe illness.